

**Grant 12-004**

**PI: Diane Epperly**

**Title: South Carolina Spinal Cord Injury Association (SCSCIA)  
Cooperative Agreement**

**Year 4 Report: November 1, 2015 – October 31, 2016**

**Goals and Objectives**

**Goal 1: Foster a climate in which spinal cord injury research is relevant and engaging to individuals with spinal cord injuries and the professionals who serve them.**

**Objective: 1.1:** (COMPLETED) Utilize Breeze group network, community events, and other one-on-one contact to register at least eight individuals with spinal cord injuries in SCSCIA's research database.

A total of 24 people registered from November 1, 2015 through April 30, 2016 from 12 counties in South Carolina.

A total of 35 people registered from May 1 to October 31, 2016 from 14 counties in South Carolina.

**Objective 1.2:** (COMPLETED) Identify on-site, telephone, and online spinal cord injury research studies that offer participation opportunities for individuals with spinal cord injuries. Promote, at least monthly, through website, social media and email blasts.

In addition to studies specific to spinal cord injury, SCSCIA has broadened the scope of studies promoted to people with spinal cord injuries. This enables people to get more involved in research and to hear about a range of studies on a regular basis. It's also served to establish research promotion as a significant focus of the association.

November 2015:

Even though this study was not yet recruiting participants, it was posted on the SCSCIA website since it is a relevant, SCIRF-funded study.

*Development and evaluation of multimedia and technology-enhanced components of a telehealth SCI self-management intervention (2015 P-02)*

PIs Susan Newman, Ph.D. and Mathew Jon Gregoski, Ph.D.

College of Nursing, Medical University of South Carolina  
Charleston, SC

December 2015:

The following studies were posted on the SCSCIA website and Facebook:

*Spinal Reflex Training Research Study*

PI Aiko Thompson

Center for Rehabilitation Research in Neurological Conditions at  
Medical University of South Carolina

Charleston, SC

*Online Study of Accessible Wireless Devices and Services\**

John Morris Ph.D.

Shepherd Center in conjunction with the Rehabilitation Engineering Center for  
Wireless Technologies

Atlanta, Georgia

\*This study was also posted on Twitter.

*Chronic Pain Web-Based Research \**

PI Jeanne Zanca, PhD, MPT

Kessler Foundation

West Orange, New Jersey

\*This study was also promoted through SCSCIA's email distribution list.

January 2016:

The following studies were posted on the SCSCIA website and Facebook:

*The Effects of Intermittent Hypoxia on Leg Function in Persons with Spinal Cord Injury*

PI Randy Trumbower, PT, Ph.D.

Emory University

Atlanta, Georgia

*Dose-Response Effects of Whole Body Vibration on Spasticity and Walking in SCI*

PI Edee Field-Fote, PT, PhD, FAPTA

Shepherd Center

Atlanta, Georgia

*Peer Influence on Intrauterine Contraceptive Behavior and Attitudes in an Online Social  
Community \**

PI Damon Centola, Ph.D.

University of Pennsylvania, Annenberg School of Communication

Philadelphia, Pennsylvania

\*This study was also posted on Twitter.

The following study was sent out through SCSCIA's email distribution system:

*Disability and Employment*

The University of South Carolina and the SC Disability Employment Coalition

Columbia, SC

February 2016:

The following studies were posted on the SCSCIA website and Facebook:

*Race and Ethnicity Collection in the VA Health System*

Contact: Aleatha W. Fields

Ralph H. Johnson VA Medical Center

Charleston, SC

\*This study was also posted on Twitter.

*Assistive Technology to be Used in Other Countries to Develop and AT Plan*

Contact: Andrea Pupulin  
World Health Organization

*Aim2Quit SF*

PI Ricardo F. Muñoz, PhD.

Latino Mental Health Research Program at the University of California, San Francisco, California; The Institute for International Internet Interventions for Health (i4Health) at Palo Alto University, Palo Alto, California; The Center for Behavioral Intervention Technologies (CBITs) at Northwestern University, Evanston, Illinois

March 2015

The following studies were posted on the SCSCIA website:

*Telephone-based Diabetes Research Study for African Americans*

PI Dr. Leonard Egede  
Medical University of South Carolina  
Charleston, SC

*Survey on Urinary Tract Infection Symptoms in Individuals with Spina Bifida and Spinal Cord Injury \**

Contact: Inger Ljungberg, MPH  
MedStar National Rehabilitation Hospital  
Washington, DC

\*This study was also posted on Facebook.

April 2016

The following studies were posted on SCSCIA's website, Facebook and Twitter:

*A Long-Term Outcomes Study to Assess Statin Residual Risk Reduction with Epanova in High Cardiovascular Risk Patients with Hypertriglyceridemia\**

PI James Thomas  
Medical University of South Carolina  
Charleston, SC

*Online Study of Interpersonal Memory Processes*

Contact: Dr. Janice R. Kelly  
Perdue University  
West Lafayette, Indiana

*Happily Ever After? The Relationships & Movies Study*

PI Dr. Ronald Rogge  
University of Rochester Department of Clinical and Social Sciences in Psychology  
Rochester, New York

Note: While they were not studies promoted in May and October, the other months in the quarter have multiple studies listed.

June 2016

The following studies were posted on SCSCIA's website, Facebook and Twitter:

*Impact of Probiotics on Urinary Symptoms in spinal cord injury and spina bifida*

PI: Inger L Ljungberg, MPH  
Medstar Research Institute  
Washington, DC

*Clinical Trial of Phone Apps for Individuals With SCI/D*

PI: Bradley Trumppower, MS  
University of Michigan  
Ann Arbor, MI

*Long-term Outcomes and Life Satisfaction of Adults With Pediatric-Onset Spinal Cord Injuries*

PI: Kathy Zebracki, Ph.D  
Shriners Hospitals for Children  
Chicago, IL

July 2016

*Hypertension Study*

PI: Alvin Jackson  
Southeast Regional Research Group  
Savannah, GA

*Marital Satisfaction Study*

PI: Elizabeth Reyes-Fournier, PhD  
Keisler University  
Fort Lauderdale, Florida

*Finding Partners in the 21st Century Study*

PI: Ron Rogge, PhD  
University of Rochester  
Rochester, NY

*Spinal Cord Injury Research with High Altitude Breathing Treatments*

PI: Dr. Randy Trumbower, PT, PhD  
Emory University  
Atlanta, GA

August 2016

*Research Study on Nutrition Education in Individuals with Spinal Cord Injury*

PI: Jesse Lieberman, MD, MSPH  
Carolinas Rehabilitation  
Charlotte, NC

*User Testing and Evaluations of Televideo Systems*

PI: Jenay Beer, PhD

University of South Carolina Assistive Robotics and Technology Lab  
Columbia, SC

*Air Travel for Individuals who use Wheelchairs*

PIs: Peter Axelson MSME RE ATP and Jessica Presperin Pedersen MBA, OTR/L, ATP/SMS  
Beneficial Designs and the Rehabilitation Institute of Chicago  
Chicago, IL

September 2016

*Shaving/Facial Care Application for People With Limited Hand Function*

PI: Aaron Hannon

St. Muredach's College  
Ireland

*MS Survey of Disease-Modifying Drugs*

PI: MS Coalition

United Spinal Association  
New York

*Supporting Patient Care With Electronic Resources in the United States*

PI: Hyon Choi, MD, DrPH

Massachusetts General Hospital  
Boston, MA

*Rheumatoid Arthritis (RA) Study*

PI: Sharan Rai

Massachusetts General Hospital & Harvard Medical School  
Boston, MA

**Objective 1.3:** (COMPLETED) Provide quarterly research updates to individuals in SCSCIA's research database.

December 2015:

An email was sent out to members on the SCIRF research list. Jeanne Zanca, PhD, MPT from Kessler Foundation is conducting chronic pain web-based research. This research study will help them learn if two different web-based education programs reduce pain's interference with daily activities and improve well-being in people with SCI and chronic pain. The email was sent to 75 individuals on the research list.

An email was sent to members on the SCIRF research list. Aiko Thompson at the Center for Rehabilitation Research in Neurological Conditions at MUSC is conducting clinical research focused on restoring function in individuals who have sustained spinal cord injuries. They are currently recruiting volunteers who are interested in

participating in a spinal reflex training research study (for those with an incomplete injury up to T-12). The email was sent to 75 individuals on the research list.

An email was sent to members on the SCIRF research list. John Morris, Ph.D., from Shepherd Center, was conducting a study to educate the wireless industry and the general public in order to promote usability of accessible wireless devices and services for people of all ages and abilities. This was an online study and 75 individuals were sent the email.

January 2016:

An email was sent to women on SCIRF research list. Principal Investigator: Damon Centola, PhD of the University of Pennsylvania is doing a study titled Peer Influence on Intrauterine Contraceptive Behavior and Attitudes in an Online Social Community. The study is online. Participants receive \$25 for participating for 12 days and completing a survey. Eleven women met the criteria for participation.

February 2016:

A mailing was sent to all members on the SCSCIA database to recruit members for the research notification list. The mailing highlighted several studies including Chronic Pain Web-Based Research from the Kessler Foundation, a nutrition study from Carolinas Rehabilitation Hospital in Charlotte, North Carolina, Online Peer Influence on IUD Behaviors and Attitudes from the University Of Pennsylvania Annenberg School Of Communication, and a research study on attitudes of people with disabilities in the workplace from Colorado State University. The mailing was sent to 1,100 individuals with spinal cord injuries.

An email was sent out to members on the SCIRF research list. The study being conducted through the Veterans Administration and MUSC will look at Race and Ethnicity Collection in the VA Health System. The email was sent to 80 individuals on the list.

An email was sent out to members on the SCIRF research list. The World Health Organization conducted an online research study on assistive technology to be used in different countries to help them develop an AT plan. Eighty individuals on the research list were sent the email.

An email was sent out to members on the SCIRF research list. A bilingual online research tool to help people quit smoking was developed by i4Health at Palo Alto University in California. Eighty individuals were sent the email.

March 2016:

An email was sent to members on the SCIRF research list. Medstar National Rehabilitation Hospital in Washington, DC conducted a study on urinary tract infection symptoms of people with spinal cord injury and spina bifida. The email was sent to 89 individuals on the research list.

An email was sent to African Americans on the SCIRF research list. This was a telephone-based diabetes research study for African Americans conducted at MUSC by Dr. Leonard Egede. The email was sent to 37 individuals.

An email was sent out to the members of the SCIRF research list with a link to our research studies webpage. Members were informed about the current research closing before April 2016. The email was sent to 90 individuals.

April 2016:

An email was sent out to members of the SCIRF research list. The email contained links to four studies at MUSC, Purdue University, and the University of Rochester. The MUSC study was an Epanova® Study. The Purdue University study was on interpersonal memory processes. Two studies were from the University of Rochester on correlations between relationships and movies. The email was sent to 92 individuals.

June 2016

A flyer was sent out to 25 people on the SCIRF research list who don't have email. It promoted the following studies: *Chronic Pain Web-Based Research*, *Research Study on Nutrition Education in Individuals with Spinal Cord Injury*, *Survey on Attitudes on People with Disabilities in the Workplace*, *Study on Online Peer Influence on IUD Behaviors and Attitudes*.

An email was sent out to members of the SCIRF research list. The email invited readers to look at all studies posted on the association website and provided a link to the list.

July 2016

An email was sent out to members of the SCIRF research list. The email invited readers to look at all studies posted on the association website and provided a link to the list.

August 2016

A flyer was sent out to 25 people on the SCIRF research list who don't have email. It promoted the following studies: *Spinal Cord Injury Research with High Altitude Breathing Treatments*, *Hypertension Study*, *Finding Partners in the 21st Century Study*, *User Testing and Evaluations of Televideo Systems*, *Marital Satisfaction Study*.

An email was sent out to members of the SCIRF research list. The email provided links to the following studies on the association's website: *Research Study on Nutrition Education in Individuals with Spinal Cord Injury*, *User Testing and Evaluations of Televideo Systems*, and *Air Travel Study With Individuals who use Wheelchairs*.

September 2016

A flyer was sent out to 25 people on the SCIRF research list who don't have email. It promoted an *iPad Usability Study* being conducted by Susan Newman and Mathew Jon Gregoski, MUSC College of Nursing (SCIRF #2015 P-02 *Development and evaluation of multimedia and technology-enhanced components of a telehealth SCI self-management intervention*).

**Objective 1.4: (COMPLETED )** Feature a detailed article about a researcher or a particular research study in one issue of the *Outspoken* newsletter and a shorter article in the other issue.

The summer issue of *Outspoken* included a feature article about the current research of Victoria Turgeon, Ph.D. on *Establishment of cellular model systems to investigate and manipulate the hostile environment produced by thrombin following spinal cord injury (2015 I-02)*.

The fall issue of *Outspoken* included a feature article about SCSCIA board member Susan Newman's research: *Development and evaluation of multimedia and technology-enhanced components of a telehealth SCI self-management intervention, SCIRF #2015 P-02)*

**Goal 2: Incorporate an increased focus on research in the association's in-service education to make a greater impact on rehabilitation professionals.**

**Objective: 2.1: (COMPLETED)** Provide two in-services per quarter to professionals at rehabilitation hospitals, home health care agencies, acute care hospitals, and/or Vocational Rehabilitation area offices.

The association's in-services educate professionals on the services offered by the association that can assist their patients or clients. SCSCIA's relationship with SCIRF and focus on research is covered in the in-services.

The following in-services were provided:

November 9, 2015: For Vocational Rehabilitation Staff, Greenville  
November 12, 2015: For Vocational Rehabilitation Staff, Columbia  
November 16, 2015: For Vocational Rehabilitation Staff, Florence  
December 16, 2015: For Vocational Rehabilitation Staff, Charleston  
March 15, 2016: Springs Memorial Hospital Rehabilitation Services staff, Lancaster  
July 11, 2016: Spartanburg Rehabilitation Institute, Spartanburg  
September 12, 2016: Palmetto Health Richland, Columbia

SCSCIA also provided a three-member "Living with Spinal Cord Injury" panel at the "Caring for the Whole Person Spinal Cord Injury Conference" in Asheville, North Carolina, hosted by the Mountain Area Health Education Center in Asheville. The panel consisted of three individuals with spinal cord injuries who answered questions from professionals on a range of topics, including managing healthcare, equipment to enhance independence, accessibility, and relationships.

**Goal 3: Promote prevention of spinal cord injury utilizing the national ThinkFirst injury prevention program.**

**Objective 3.1: (COMPLETE)** Recruit and train two additional *Voices of Injury Prevention* volunteer speakers to conduct presentations in public and private schools.

Ria Saxon and Alex Jackson of Charleston were recruited and trained as *Voices of Injury Prevention* volunteer speakers.



**Objective 3.2:** (COMPLETED) Schedule a total of 40 presentations in middle and elementary schools to reach an estimated 800 students.

Between November 1, 2015 and October 31, 2016 the following presentations were done:

November 9, 2015  
Ben Lippen School  
7<sup>th</sup> graders  
3 Presentations  
55 students

February 22, 2016  
Hand Middle School  
4 presentations  
95 Students

March 22, 2016  
Longleaf Middle School  
4 presentations  
104 students

March 23, 2016  
Longleaf Middle School  
4 presentations  
111 students

December 9, 2015  
Busbee Creative Arts Academy  
7<sup>th</sup> graders  
1 presentation  
21 Students

December 11, 2015  
Busbee Creative Arts Academy  
7<sup>th</sup> graders  
4 presentations  
93 students

April 26, 2016  
Gilbert High School  
12<sup>th</sup> graders  
1 presentation  
120 students

May 16, 2016  
Dutch Fork Middle School  
7<sup>th</sup> Graders  
4 classes  
79 students

May 18, 2016  
Gilbert Elementary  
10 classes  
240 students

May 19, 2016  
Dutch Fork Middle School  
4 classes  
90 students

June 24, 2016  
Victory Missionary Baptist Church, Springfield  
1 presentation  
13 students

August 13, 2016  
St. Matthews Baptist Church, North Charleston  
1 presentation  
17 students

Total number of presentations: 41  
Total number of students: 1,038

**Objective 3.3:** Conduct (COMPLETED) at least one ThinkFirst presentation in an alternate setting than a school and outside of the Midlands.

A ThinkFirst presentation was held on August 13 at St. Matthews Baptist Church in North Charleston for members of a local Boy Scout troop. Two new VIP speakers, Ria Saxon and Alex Jackson, participated in the presentation.

**Goal 4: Continue to support leadership and members of Breeze groups to sustain strength of local Breeze group network.**

**Objective 4:1:** (COMPLETED) Enhance engagement in Breeze groups by increasing staff attendance at each of the seven Breeze groups from once a year to twice a year.

The following staff visits were made to Breeze groups:

Greenville:

Angela Jacildone, April 21, 2016  
Diane Epperly, July 21, 2016  
Angela Jacildone, September 15, 2016

Orangeburg:

Diane Epperly, December 10, 2015  
Angela Jacildone, April 14, 2016

Rock Hill:

Angela Jacildone, December 15, 2015  
Diane Epperly: September 20, 2016  
Angela Jacildone, June 21, 2016  
Angela Jacildone, August 16, 2016  
Angela Jacildone, October 22, 2016

Trident:

Angela Jacildone, December 8, 2015  
Angela Jacildone, September 13, 2016  
Diane Epperly was scheduled to attend October 15 meeting, but it was cancelled due to park closure after Hurricane Matthew.

Spartanburg:

Diane Epperly, August 16, 2016  
Angela Jacildone: May 17, 2016  
Angela Jacildone, September 20, 2016

Horry County:

Angela Jacildone, November 4, 2015  
Diane Epperly, April 6, 2016

Florence (Organizational)

Diane Epperly and Angela Jacildone: August 30  
Angela Jacildone: September 28

Midlands: Diane Epperly and Angela Jacildone attend every meeting.

**Objective 4.2:** (INCOMPLETE) Create board involvement with Breeze groups by board members attending a Breeze group meeting outside of their cities of residence.

Six of 13 board members made visits. The following visits were made to Breeze groups:

Midlands: Alex Jackson, January 5, 2016  
Dot Colson, February 23, 2016

Rock Hill: Robin Crawford, February 19, 2016  
Eugene Rowell, February 19, 2016

Horry County: Josh Merryman, April 30, 2016

Florence: George Stabler, August 30, 2016

**Objective 4:3:** (INCOMPLETE) Strengthen relationships between Breeze leaders by each leader of the seven established Breeze groups attending another Breeze group meeting.

**The following visits have been made:**

Spartanburg: Dennis Koch < Greenville Leader, December 2015

Midlands: Terry & Donna Short, Rock Hill Leaders, February 2016

Dot Colson, Spartanburg Leader, February 2016

Horry County, Barbara Delia, Trident Leader, April 2016

Trident: Veronica Tario, Horry County Leader, April 2016

Rock Hill: Alicia Reagan, Midlands Leader, November 2015

Rebecca Felder, Orangeburg leader, was scheduled to visit the Spartanburg group, but was unable to make the trip.

**Objective 4.4:** (IN PROCESS) Add one new Breeze group to expand the reach of the association into another local community.

Staff made contact by mail and phone with registered members in Aiken County to determine interest in a Breeze group. Outdated phone numbers were a major obstacle. There was not sufficient interest to proceed in that area.

Staff went through the same procedure in Florence County. Thirteen individuals positively responded to the idea of a new group in their county. An initial introductory meeting was held on August 30 and attended by 13 people. A second meeting was only attended by one individual, yet this person agreed to take on leadership of the group. He will undergo leader training and staff will work with him to plan first three meetings. First meeting will be held after the first of the New Year.